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PRINCIPAL INVESTIGATOR: Jack A. Clark, Ph.D.

CONTRACTING ORGANIZATION: Boston University  
Boston, Massachusetts 02118

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<b>13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information)</b> To examine men's perceptions of life transitions associated with prostate cancer through an analysis of their narratives, obtained in in-depth, qualitative interviews; compare men's narratives of perceived transitions with respect to quality of life outcome states, i.e., good vs. poor prostate cancer-related quality of life. Phase 1: interview participants in our quality of life survey of previously treated patients, stratified by quality of life. Phase 2: interview members of our prospective cohort who have completed 36-month followup, stratified by quality of life states and observed changes in urinary, bowel, and sexual function. Phase 3: prospectively interview patients with new diagnoses of early prostate cancer prior to treatment and 12 months later. Comparative analyses, with comparisons between strata and the three cohorts, will characterize the structure and content of patients' narratives of prostate cancer, including specific changes in identity and interpersonal relationships, that are linked to quality of life outcomes. Interviews conducted so far include: Phase 1, 17; Phase 2, 0; Phase 3, 11. Survey instrument to identify quality of life strata in prospective cohort (n=350) has been developed, to be in field by 5 August, 2002. Analysis of completed interviews is in progress; no reportable findings as yet.				
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## INTRODUCTION

An estimated 145,000 American men, mostly aged 50 and older, will be told by their doctors that they have early prostate cancer this year. For many, if not all, this news will precipitate a crisis. They will be confronted with an ominous diagnosis and asked to make choices between a growing number of therapeutic alternatives (radical prostatectomy, external beam radiotherapy, brachytherapy, cryosurgery, observation/expectant management) in a context of uncertainty. While none of the active treatment alternatives has been shown to offer an efficacy advantage over observation, each is associated with long-term urinary, bowel, and sexual complications, which may have substantial effects on quality of life. Most of these men will survive for many years, some living with problematic treatment-related physical changes, psychosocial changes, and the possibility that treatment did not eliminate prostate cancer as a serious threat. The growing appreciation of the salience and magnitude of these effects, for both individual patients and an aging population, has resulted in advances in our knowledge of quality of life outcomes, informed by improved methods for measuring prostate cancer-related quality of life. Yet, our understanding of how men respond cognitively and emotionally to the diagnosis of prostate cancer and its treatment remains limited. In particular, we lack information about how men perceive the changes they go through, from their pre-treatment state to their health and quality of life state after treatment.

However, advances in social and behavioral science methods for studying how people perceive and make sense of their own lives through personal narratives offer a productive approach for research on the changes in quality of life that may be occasioned by the diagnosis and treatment for early prostate cancer. Narratives have clearly identifiable grammatical structures. They can be rigorously analyzed as meaningful social objects. Moreover, there is growing interest in patients' narratives of their illnesses within the medical community. Clinicians and researchers are regaining an appreciation for patients' stories, an interest as ancient as Hippocrates, since the stories individuals tell about themselves when ill reveal the ways in which they understand their illnesses and the impacts of illness on their lives.

Our study will extend a productive line of research on men's perceptions of the physical and psychosocial impacts of prostate cancer. We have developed questionnaires, research designs, and substantial databases for studying men's perceptions of the physical complications of treatment for early prostate cancer and the psychosocial impacts of these complications, as well as the emotional, symbolic effect of a cancer diagnosis. Much of this work has been strongly informed by what men say in open-ended discussions of their experiences, such as focus groups. Often, when asked to describe in their own words the impact of prostate cancer, men will begin by saying something like, "Well, it's a long story."

In this study, we will build on our previous research, particularly our well developed quantitative databases, to collect and analyze systematically men's narratives of prostate cancer, and examine their relationship with physical and psychosocial outcomes of care. We will proceed in three phases. First, we will identify men who have completed psychosocial questionnaires in our current survey of quality of life outcomes, and who fall into one of several contrasting outcome groups, that is, good or poor quality of life. We will interview these men, all of whom were diagnosed 12 to 48 months previously, elicit their narratives, and compare the stories associated with either good or poor quality of life. Second, we will verify the findings of the first phase by replicating the analysis among men who have participated in a long-term

follow-up study of physical complications of treatment. Thus, we will also examine the association between men's stories and carefully observed physical changes in urinary, bowel, and sexual function. Third, we will directly examine developing stories of the impact of prostate cancer by prospectively interviewing a small group of newly diagnosed men at two points in their prostate cancer "careers," shortly after diagnosis and 12 months later.

## **BODY**

Task 1: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a sample of previously treated patients, Months 1-12.

- a. Identify subsample of 40 respondents to prostate cancer quality of life survey, defined by quality of life outcome status
- b. Conduct in-depth interviews with subsample of respondents.
- c. Analyze men's narratives of their lives with early prostate cancer.

The subsample has been identified and interviews are in progress. At present, 17 interviews have been completed. A total of 62 respondents have been contacted by mail in order to request an interview. Of these, 14 had died or moved with no forwarding address since completing the previous survey in 1999/2000; 7 could not be reached by telephone; 24 refused to participate. All completed interviews have been transcribed and entered into the qualitative database. Analyses are underway as additional interviews are completed.

Task 2: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a cohort of patients in which urinary, bowel, and sexual function have been monitored from pre-treatment baseline to 36 months post-treatment, Months 13-24

- a. Administer survey, using patient-centered quality of life measures, to members of prospective cohort.
- b. Identify subsample of 40 respondents to quality of life survey, defined by changes, from pre-treatment status, in urinary, bowel, and sexual function, and by quality of life status.
- c. Conduct in-depth interviews with subsample of respondents.
- d. Analyze men's narratives of their lives with early prostate cancer.

A survey instrument, based on the instrument developed in our previous survey of prostate cancer patients, has been developed and printed. The cohort of 350 patients who have completed 36 months of follow-up in the Talcott/Clark prospective survey of urinary, bowel, and sexual function following treatment for early prostate cancer has been identified. Contact information has been organized into an Access database. Survey data collection will commence the week of 5 August, 2002. Identification of the interview sample will commence after survey data are collected, approximately September, 2002.

Task 3: Characterize men's prospective perceptions of life transitions associated with early prostate cancer in a cohort of patients observed prior to treatment and 12 months following the initiation of treatment, Months 10-27.

- a. Identify and recruit cohort of 40 patients with newly diagnosed early prostate cancer at two sites: VAMC's at Buffalo, NY and Washington, DC.

- b. Conduct baseline, in-depth interviews
- c. Conduct 12-month follow-up interviews.
- d. Analyze men's narratives of their lives with early prostate cancer.

At present, 48 potentially eligible patients have been identified at the Buffalo VAMC. A total of 22 have been excluded because of likely metastatic disease or already treated by the time initial contact made; 11 have refused. Currently, 2 have just been sent initial contact letters, 2 are as yet undecided about treatment (hence, interview is pending), and 11 have completed baseline interviews. Completed interviews have been transcribed and entered into the qualitative database. Analysis is in progress as data collection continues.

Task 4: Complete comparative analysis of narratives elicited in three cohorts, Months 28-34

Pending completion of interviews.

Task 5: Complete final report, Months 35-36.

Pending completion of analyses.

## **KEY RESEARCH ACCOMPLISHMENTS**

none to date, as data collection is in progress

## **REPORTABLE OUTCOMES**

There are not reportable findings from this study as yet, as data collection is in progress.

The research team has been expanded by the addition of Dr. Lorrie Powel. Her study of quality of life outcomes associated with post-prostatectomy urinary incontinence has been supported by DoD as a post-doctoral training grant, under the supervision of Dr. Jack A. Clark (DAMD17-02-1-0236). Dr. Powel brings extensive clinical experience in nursing to the project. While Dr. Powel's project is a separate undertaking, her training will include participation in the analysis of data collected in the present study. In addition, Dr. Barbara G. Bokhour, co-investigator, has recently completed the first year of a two-year study, funded by the National Cancer Institute (RO3 CA 91737001), to explore the clinical utility of the qualitative findings derived from the present study. As a result, the overall project has been strengthened by clinical expertise and an direct examination of the clinical utility of the findings, as they emerge.

## **CONCLUSIONS**

Subject accrual is progressing about as expected at the Buffalo site. However, subject accrual has not been initiated at the Washington DC site (phase 3) because of substantial delays in the granting of final approval by the local IRB. The IRB was audited by the VA in the Fall and Winter of 2001/2002, resulting in significant delays in the processing of protocols. While

we anticipate that this problem will be resolved shortly, we are also exploring the inclusion of an additional site: the urology clinic at Boston Medical Center. The investigators have a relationship with this clinic, developed in previous studies. The clinic also serves a racially and economically diverse population, thus it would be suitable to the goals of the study, including analyses of quality of life changes associated with treatment for early prostate cancer in a diverse population.

The results of this study will be useful in several ways. They will guide the design of future, large scale studies of the processes and outcomes of care for early prostate cancer. Yet, they will have more immediate utility. They will provide informative materials for health care providers about the significant changes men see themselves as undergoing. They will also provide information to men who face the ominous diagnosis and those who continue to live with the outcomes of their treatment. Moreover, we will provide information about the changes men experience in the understandable form of men's stories.

## **REFERENCES**

none

## **APPENDICES**

none